

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

[]

The Developmental Disabilities Special Investigative Committee met at 1:30 p.m. on Thursday, October 16, 2008, in Room 1524 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing regarding Beatrice State Developmental Center. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Abbie Cornett; Arnie Stuthman; and Norm Wallman. Senators absent: Tim Gay. []

SENATOR LATHROP: Good afternoon, everyone. My name is Steve Lathrop. I'm Chair of the commission that was put together by the Legislature to look into the state's delivery of services to the developmentally disabled and also to look into what we generally refer to as the Beatrice situation. We've had hearings since, I think, June and taken up various topics. Today we're going to take up...this afternoon we're going to take up the waiting list. And we became aware of the waiting list as we were doing our investigation and thought it merited some discussion, so we're glad you're here today. I want to introduce my colleagues who are part of the commission. To my immediate left is Senator Arnie Stuthman from Platte Center, which is generally in the Columbus area; Norm Wallman, who is in the district that includes the Beatrice Development Center; Greg Adams to my immediate left from York; Doug Koebernick, who is my assistant; and then Senator John Harms from Scottsbluff; and Abbie Cornett from Bellevue; and then our able clerk, Beth Otto. You're all invited, those of you that wish, to testify. There are a few ground rules that I'd like to explain to you. We have sheets here and, so that Beth can keep a good record of who has testified and we can call you up if we need to get any additional information, we'll ask you to each fill out a sheet and place it in a box when you testify. That's really the primary ground rule. We are going to begin with two different people that have asked to speak, and then we'll kind of open it up, and one is going to be Mary Gordon whose LR156 group is working on the waiting list. And so I think to the extent that they've done some of their work already, we might as well take advantage of that and so I've asked Mary to testify and she'll go first. And then we'll

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

have Bryan Patel, who's with the Teamsters, and they do some of the work in some of the community-based programs and he's going to testify quickly because he's got to move on and get to a different meeting. So after that, after those two have testified, please feel free to fill in the front row and if you want to testify or be heard on the subject of the waiting list, please, today is the day and we'll look forward to hearing from you. Thanks. And, Mary, we'll let you start. []

MARY GORDON: (Exhibit 1) Good afternoon, Senator Lathrop and members of the Developmental Disabilities Special Investigative Committee. My name is Mary Gordon, G-o-r-d-o-n, and I am director of the Nebraska Planning Council on Developmental Disabilities. Although the council is appointed by the Governor and administered by the Department of Health and Human Services, the council operates independently and our comments do not necessarily reflect the views of the Governor's administration or the department. We are a federally mandated, independent council, comprised of individuals and families of persons with developmental disabilities, community providers, and agency representatives that advocate for system change and quality services. I have been invited to speak to you today about the council's activity related to the waiting list for DD services. Legislative Resolution 156 of the First Session of the One Hundredth Nebraska Legislature charged the Department of Health and Human Services to establish a work group to: one, submit recommendations for a strategic plan to incrementally reduce the number of persons on the waiting list for developmental disabilities to meet the intent of the Legislature; two, consult with the Department of Health and Human Services to review and make recommendations to any revisions to the rate methodology; and three, submit the work group's recommendations on the strategic plan and revisions to the state methodology in a report to the Medicaid Reform Committee, the Legislature, and the Governor. After a discussion with Senator Johnson, the department asked the Nebraska Planning Council on Developmental Disabilities in December of 2007 to oversee the work group and its activities. We're a very small program. There's really only two professional staff and, as a result of my own cancer treatment and the need to go through the state bid process to ensure that a neutral

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

facilitator for the work group was elected, the first meeting did not occur until October 1. Three additional meetings are scheduled and the report will go to the council for their review and approval in early December. The final report is due December 15, 2008, and we will hopefully get it to you all first and then to the rest of the Legislature. I have given you a copy of a handout given to the work group at their first meeting. It's titled "Understanding the Waiting List," and it was prepared by the LR156 work group facilitator using data supplied by Health and Human Services. First of all, I'd like to share with you some general things that the work group is looking at. First, the waiting list itself is very complicated and not always understood the same by everyone. In Nebraska, individuals with developmental disabilities or their families may put their names on a registry to indicate that they may need services. When they do this, they are asked for a date on which they will need the requested service. They can choose today's date, or the date they put in their name, or a future date. The term "waiting list" refers to the subset of people on the registry who are past the date that they requested services. However, since most people know that services are not available when needed, they may select a service date to allow for this delay. For example, if people need services in 2013, they may record their service date as 2008 to try to ensure they will get services when they do need them. Of course, this means that the actual number of persons on the waiting list may be inflated, and the DD Division reported to the work group that almost 30 percent of the people offered services turned them down and postponed to a future service date. So to just hopefully clarify, it's not that those numbers are wrong or when I said inflated, I didn't mean they're more. It's just that the past...the ones on the waiting list may not really be waiting. They may need them in the future, but they put their name as of that date just so they can make sure they get them when they do need them. Under the traditional DD Medicaid waivers, which I know you all have heard about so I'm not going to bore you with it, but there are basically three types of services that individuals are waiting for: day services, which are typically vocational but may be some others; residential services; and respite. The majority of individuals on the waiting list are waiting for residential services. As of July 1, 2008, there were 1,865 persons waiting for services. Of these, 1,628 of them were waiting for

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

residential services, and this is primarily because Nebraska has offered day services as an entitlement to Nebraska youth who graduate from a Nebraska high school at age 21 since 1993. As senators, you may hear from two other groups that have concerns about services they need, but these individuals are not on the waiting list that we are discussing. The first group is individuals who have been approved for the needed units of service but, because of where they live or the difficulty of finding a provider willing to serve there...serve them, are unable to make use of all the units that have been authorized. An example of this is individuals with complex medical needs living in rural areas. Their medical conditions do not permit their being transported to a workshop or day program, and an appropriate person to come to the home is not available. Although these individuals are not on any waiting list, the Developmental Disabilities Division is able to identify these people since they are billing for less than authorized hours. A second group of individuals are those people who are receiving a service but the authorized hours are less than the assessment has determined is needed or less than some members of the team feel is needed. These are the underserved. This group is much harder to identify and is not kept on any waiting. Our work group is looking at the waiting list but also discussing these other two groups, as any system change will have an impact on all of them. Obviously, we've only had one meeting so it's too early in the process to have recommendations for you, but I will share with you my sense of what the group is considering. Obviously, there will be need for additional funding. Even if we believe that 30 percent of the people on the list will postpone their request when offered a service, that still leaves a large number of individuals, over 1,300, that will accept. However, funding is not the only answer. The same need for qualified direct service workers which you have been hearing about in relation to BSDC exists in the community. Low staff salaries and training issues are identified problems. Providers have indicated that it takes about one person hired for every one person served, so that will mean a hiring of almost 1,300 people to serve, or 1,800 if you look at the full list. The actual labor pool out there for that many individuals is going to be a real challenge for our state. Accessible housing and city ordinances can limit the development of traditional residential settings, such as group homes. As a result, the work group is

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

looking at more flexible models of service delivery to maximize resources and ensure the programs are achieving the best outcomes for people's lives in the most cost-effective way. This includes the community supports waiver and Nebraska's high-cost expense in using habilitation as the primary waiver service. As far as training, the Nebraska Planning Council is making grant funds available to DD providers to pilot the Collect of Direct Support--a national, Internet-based learning program for direct support staff. It has been proposed at the LR156 meeting that changes in the way the state manages and prioritizes the waiting list may make it a more useful tool and enhance capacity. The method of paying for DD services is also being reviewed to determine its impact on the waiting list and if changing this rate methodology could help decrease the waiting list and use current resources more effectively. As you can see, there's not an easy answer to addressing the waiting list. Our work group is identifying issues, including reviewing past recommendations, to make current recommendations that Nebraska can use to decrease the waiting list. Just want to mention, prior to my coming up here, Senator Lathrop had asked about data. We do have quite a bit of data we've gotten from the Developmental Disabilities Division on the waiting list and I will share that with Doug and he, obviously, will be able to share it with you all. Just didn't want to overwhelm you with paper today as we...because it is a lot, but we're trying to put it in an order to understand it. And I thank you, and if anyone has any questions I'd be glad to try to answer them. []

SENATOR LATHROP: Sure. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Mary, thank you for coming and giving us this information. Can you give me an example of an individual with developmental disabilities that would need services, like you state, in 2013? Why would you request it at that time? Give me some type of an example of why that would be. []

MARY GORDON: Okay. For example, I may have a 16- or 17-year-old son or daughter or a 25-year-old and I know that I want a group home. I'm going to retire, move out of

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

the state, something, so for some reason I know that I want a group home and, in my mind, I'm thinking, well, by the time 2013, either they'll be 22 or 23, my other children have moved out by then, that's when I'm going to want a group home. But I know that when that time comes and they are 23 or 24, there might be a five-year list. It might take five years to get it. So I go ahead and put my name on the list saying I need it now--even though my child is only 16, or 17, or 25, or whatever--then when that...hoping that when that time comes, I will need it. What sometimes happens, Senator, is that when that time comes and it is offered to me, things may have...my life may have changed. Suddenly my 24-year-old, you know, we're not moving, I'm not retiring, they're in good health, I'm in good health, they have a job and so everything is fairly settled at home and so I may say, no, I don't need it now, maybe five years from now I may need it, so then I'll put 2018 on the list. So I don't know if that... []

SENATOR STUTHMAN: Yes. Yes, that helps me a lot. It's you're planning for the future... []

MARY GORDON: Right. []

SENATOR STUTHMAN: ...for your own health and age and everything. But, you know, it may not occur, but when you decide to do that, it might not be available for another five years. []

MARY GORDON: Right. []

SENATOR STUTHMAN: So, okay. Thank you. []

MARY GORDON: So you might project out,... []

SENATOR STUTHMAN: Yes. []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

MARY GORDON: ...thinking I'm going to...I really think I need it in ten years but I'm going to say five years or this year, just hopefully. []

SENATOR STUTHMAN: Okay. Thank you, Mary. []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: Mary, if I might, I'd like to clarify something. I heard you say the number is inflated, and you did a good job of explaining why that might be. Then I heard the number 1,300 and I heard the number 30 percent, and maybe they have nothing to do with the answer, but if we could...if you could deflate and get us to an approximate number of how many people right now need services, what might that be? []

MARY GORDON: I would say that it probably would be...the list right now with the 1,800, if you take off 30 percent, that's about 1,300. []

SENATOR ADAMS: Okay. []

MARY GORDON: So that's... []

SENATOR ADAMS: Okay. []

MARY GORDON: ...that's where I came up with the 1,300. []

SENATOR LATHROP: I do have a few questions for you, Mary, if I can. []

MARY GORDON: Oh, sure. []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

SENATOR LATHROP: We had some discussion about the waiting list previously and if I understand what's happening in the state of Nebraska with respect to the services provided to adults is that if you have a school-age child, which would be, in Nebraska, under 21, the services that are provided to assist in the education, which might include physical therapy... []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: ...and occupational therapy and those kinds of things, that's all going to be provided by the school district. []

MARY GORDON: Right. []

SENATOR LATHROP: So for the...for those who have developmental disabilities who are not yet 21, their needs are being met either with Mom and Dad at home plus the school district. []

MARY GORDON: Yes, primarily. Yes. []

SENATOR LATHROP: Generally true? []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: It is when those high school seniors,... []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: ...and it's about 200 in number, when they graduate, we have...we've somewhere along the way put them at the front of the line and they get to become the next 200 people to get day services. Is that true? []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

MARY GORDON: Right, yes. []

SENATOR LATHROP: And we have in Nebraska about 200 people leave the system through attrition. []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: Yes? []

MARY GORDON: Well, yes. []

SENATOR LATHROP: Okay. []

MARY GORDON: They told us about 145, so that's about right. []

SENATOR LATHROP: So we basically have as many people leaving the system as we do high school seniors or graduating high schoolers. []

MARY GORDON: Right. []

SENATOR LATHROP: So do we make any ground on the list at all? Is the list static, and people who are on it that are not folks who are just reaching 21 and graduating from high school, those folks, are they just stuck on that list? []

MARY GORDON: Yes, right now. The last time, I believe, that people got off the list was in 2006 and we had...some of you may remember there was some money set aside from the tobacco money and not all of that was spent and so that tobacco money was the last money that actually...what happens to those people, they're stuck in one. They are stuck, but what the...kind of the safety net, but it's not the best, is they do have a

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

system, what they call priority one. I call it emergency or crisis. Basically, if my parent is caring for me and has to be hospitalized or some...or something happens, then those individuals get bumped to the very top, will get additional hours. []

SENATOR LATHROP: So as we look at the list and the way the state is managing the list currently, you're there unless you abandon your ward. Whether that's your son and daughter or you're the guardian of them, you have to essentially abandon them, make them a priority one, before they're going to get off the list and start getting services. []

MARY GORDON: Right. And abandoning is not easy. []

SENATOR LATHROP: That's where we're at. []

MARY GORDON: Yes. But yes. []

SENATOR LATHROP: That's where we're at. Your estimation was that 1,865 families or persons are on the list; 1,628 of those are waiting for residential services. But even the...we have approximately 200 people leaving or 145 people leaving. Some of those are getting residential services but we move over the graduating group and they get day services and not residential services. So the number of people we're serving for residential services is getting smaller. Would that be true? []

MARY GORDON: That would be true. And just...I'm sure you know, the day services are much cheaper, obviously, than residential. Residential group homes are probably the most expensive service right now. And so what happens is, as those people who leave or die or move out of the state and drop off of residential, there's two things that happen. One is that money, because you're basically putting those 200 in to "day," which is a less costly service, that any savings you may have then goes in to pay for the priority one, for those emergency people. So that money is moving over there. The other thing that happens, and we've heard it in our work group and I'm sure you may

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

hear it as well, what happens is that loss of people leaving is creating a real problem with our providers, because the providers have...you know, they may have a home where three people or four people are in it, one person leaves or passes away or something happens, they may not get funding for someone else to come into that home. So basically, they have to either move everybody out to find new places for them to live where they can get enough hours for them, or kind of do an upset-the-applecart kind of thing to try to put together a group home setting. But...so there's kind of two...actually, there's many more effects, but that's the two that (inaudible). []

SENATOR LATHROP: That's a couple of the consequences. []

MARY GORDON: Uh-huh. []

SENATOR LATHROP: I want to ask you about your group so that I can understand and I make sure we don't... []

MARY GORDON: Sure. []

SENATOR LATHROP: ...expend our energy doing exactly what you're doing. You are, through the LR156,... []

MARY GORDON: Six, right. []

SENATOR LATHROP: ...charged with exploring or having a complete understanding of the waiting list, and do you then also issue a report for a strategy to reduce the list down to zero or something? []

MARY GORDON: Yes. Yes, that is what our...what we've been charged to do. I don't know how many years till we get to the zero, but we will be...we will be coming up with recommendations on how to reduce it. As you know, the statute actually says that it is

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

the intent of the Legislature, and it makes a reference to that, to eliminate the waiting list by 2010. Well,...so... []

SENATOR LATHROP: It's going to be a lot of work. []

MARY GORDON: It's going to be a lot. (Laugh) We've got a lot to do in the next three meetings. No, I'm just kidding. But I do think that we will be making recommendations on a plan and some ideas, because I think...and this is just my feeling, senators. I think that all of us recognize that probably we can't do things the way we're doing things and serve 18...because even if there's...you all...even if the Legislature and everyone said, we're going to give you the money to serve those 1,800 people, next year there's going to be more. Every...I mean, there...and so I think that we have to think about maybe our traditional system, our focus on habilitation. I mean the fact that habilitation, which is a very costly service, is our primary way we deliver community DD services in our state. []

SENATOR LATHROP: Are you suggesting that we might have to sacrifice habilitation in order to serve more people? Because it seems to me... []

MARY GORDON: I'm not sure... []

SENATOR LATHROP: ...that that's CMS's...I mean that's our primary responsibility for people in 24-hour care, isn't it? []

MARY GORDON: Well, yes and no. There are also services that other states are using with their Medicaid waivers for people in community-based that are not just habilitation. Habilitation is as you've heard; we relate it to active treatment. But there, you know, but there are other services. Transportation is a service. Community support, having people, you know, be more...there are less costly services. Right now, for example, and transportation is a Medicaid-approved service that could be written into the waiver. We don't have it, but if someone has a job in the community we basically...but need

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

transportation there, we have to bill it as...a provider has to bill that as habilitation to take that individual to their job. Now, granted, they may be talking to them about a job and visiting with them about a job, but to pay \$25 an hour for someone to take someone to their job may not be the most effective use of our Medicaid dollars. I'm still talking about using Medicaid waiver dollars. []

SENATOR LATHROP: Right. []

MARY GORDON: I'm not talking about get...but I'm just saying possibly expand the options of services that we do pay for under that to some less costly ones. []

SENATOR LATHROP: Okay. Any other questions? I don't see any. Thank you very much for coming down. []

MARY GORDON: Thank you very much. []

SENATOR LATHROP: We'll look forward to your information and your report. []

MARY GORDON: Okay. Certainly. Thank you, senators. []

SENATOR LATHROP: Bryan. []

BRYAN PATEL: Good afternoon, senators, Chairman Lathrop. My name is Bryan Patel. I'm a business agent with the Teamsters Local 554 in Omaha, Nebraska, and my function there is to negotiate and administrate collective bargaining agreements. One of the groups of employees that I represent is the Eastern Nebraska Community Office of Retardation, known as ENCOR, and what they do is they provide community-based services for the developmentally disabled people. The bargaining unit I represent consists of about 400 people, 200 or so in the vocational side and another 200 in the residential side. Biggest benefit that we've been able to negotiate for these folks is

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

medical insurance through Central States, which is a Teamster fund, not-for-profit. We've been able to get them a very good insurance plan. It's a 90/10 plan, \$250-\$500 deductible, vision, dental, that type of thing. One of the biggest pitfalls that we have is the extremely high turnover rate we have there and that is probably a result of what the pay is. The starting pay rate there is \$10.35 an hour, and if you do the numbers on that, at the end of the month I'm coming home with about \$1,200, and that, you know, in my opinion, is not a living wage. It's very difficult to sustain a household, let alone raise a family on that kind of money. I see two types of people, basically, that are employed there, and the first type of person I have all the respect in the world for. They do it because they want to do it. They're obviously not doing that type of work for the money. They do it because they want to do it. And the other people, the second category of people, it's really about all they could find. You know, it's just people looking for a job and the attraction for those folks for that job is, if I'm in the residential setting, I'm in a group home and I could be working, for example, a 40-hour week and I may not see a supervisor for 1 or 2 hours of that week, so I'm pretty much on my own, and that's probably where the problem comes. The funding levels being what they are, not only are they understaffed, the front-line supervisory people are understaffed as well. So if I get hired on as a residential associate, I will get some training in my orientation, some book training. But as far as hands-on training, I'm really not getting very much, if any. Pretty much sent out to the group home and if you got any problems, call me, that type of thing. That, in my opinion, diminishes the level of care that the people are receiving, and that's what it's about. You know, that's what the folks are here to do. I think another further end of the problem is the recent turn of events, I'm sure you're all aware of in Beatrice, has resulted in additional numbers of the DD people being discharged into the community-based programs and it's just putting a further burden on an already burdened system. Basically, in conclusion, the folks that I represent, you know, they have a lot of hurdles. They have substandard wages, the high turnover rate, the training is just really not there for them. That coupled with the increased numbers of people being injected in the system, I think, you know, we need to look down the road and anything that this committee, in conjunction with the Legislature, could do to appropriate

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

the funds to get better wages and better working conditions for these people so we can retain good people to do these jobs rather than just cycle through periodically the same people over and over. Because ultimately, the people that suffer at the DD people and that's not what we want. So it's really all I have. Any questions of me? []

SENATOR LATHROP: Thanks, Bryan. Any questions? I don't see any. []

BRYAN PATEL: Great. Thank you for your time. []

SENATOR LATHROP: Thanks for coming down today. Yeah. Rich. []

RICH SECOR: Good afternoon, senators, Chairman Lathrop. My name is Rich Secor, S-e-c-o-r. I'm president of a group called Village of Promise in Omaha, Nebraska, and with me today, besides myself, are five individuals from my group. We are a 17-member group that consists of various caregivers and community volunteers in Omaha, and our mission is to serve adult individuals with cognitive disabilities, those individuals that have chromosomal disorders, such as Down's syndrome, autism, and other disabilities. Our mission is to develop an integrated village, like a Boy's Town, that would ultimately one day have residential buildings, employment opportunities, recreation opportunities, as well as educational opportunities for adults with cognitive disabilities. We're an alternative to dependent living at home or dependents living in group homes. A need for our care is growing because of aging demographics. In many cases, adults with cognitive disabilities are outliving their caregivers. The longevity of their lives is increasing. The population is growing, by some of the numbers that we've been studying, and that we have estimated that there are roughly 7,900 individuals with disabilities, cognitive disabilities, in a four-county area--Washington County, Douglas County, Dodge County, and Sarpy County--and that population is expected to grow to 9,200 in the year 2020. The need...consequently, the need for long-term residential, employment, recreational care is growing, not only because of the changing demographics but also because the population is growing itself. Such care is very

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

expensive, as everybody knows. Our preliminary financial models indicate that the care for an adult with cognitive disabilities ranges anywhere from \$4,000-\$6,000 per month living outside of a home, outside of their personal residence, if their caregivers are no longer caring for them. Our surveys indicate, in our surveys with our various caregivers, that our caregivers are willing to spend anywhere from \$500 a month to \$1,500 a month toward this type of care. Consequently, there appears to be about a...anywhere from a \$2,500 to a \$4,500 a month void in terms of fulfilling the need for this care. We're very concerned about being able to fill this gap and to fill this void. We're not here today to talk about the merits of our village, and what our dream is, is to have this kind of a living environment for adults with disabilities. We're here today because we're very concerned about the ability for these individuals to be cared for in the long run. Our group today--besides myself there are five others--we're going to give brief testimony today of our own personal situations and we cover the gamut from Terri Lynch, who's a caregiver of a 35-year-old son, to Jason Tonjes, who has a daughter that's 3 years old who is just planning for the future for his daughter. So with that, I'd like to turn over to Terri Lynch and she can give her testimony. []

SENATOR LATHROP: Rich, before we let you get away,... []

RICH SECOR: Oh, okay. []

SENATOR LATHROP: ...let's make sure there aren't any questions. Anybody? I might just ask a couple just to clarify your testimony. You are with the group, Nebraska Village of Promise, and that's actually a group of parents and not a business. []

RICH SECOR: Correct. []

SENATOR LATHROP: Is that right? And... []

RICH SECOR: Parents, and we also have some community volunteers that are part of

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

our committee. []

SENATOR LATHROP: And your...we've had some discussions about this... []

RICH SECOR: Uh-huh. []

SENATOR LATHROP: ...so I have a little bit of background on it from our previous discussions, but basically your group of private individuals are interested in developing, with your own money, a village, kind of a new concept in the Omaha area is where it would be, which would provide a community environment for people with developmental disabilities. []

RICH SECOR: Yes. If you could kind of visualize what Boy's Town does, that's exactly kind of what the model that we would like to have, only instead of serving troubled teen, essentially, we're serving adults with cognitive disabilities. []

SENATOR LATHROP: Okay. And you're here today just to kind of offer your idea in the face of sort of our inspection of the delivery of developmental disability services. []

RICH SECOR: Correct. Yeah, we're very concerned about the financial means to support the adults with disabilities with this kind of care. And again, it's pervasive, whatever kind of care that these individuals get, whether or not they continue to live at home, whether they live in group homes, or whether they live in a village like what we have planned. It's all about the money and there's just not enough, unfortunately. []

SENATOR LATHROP: Right. Okay. Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, is this patterned something like after Sheldon (phonetic), Iowa, then, you know? []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

RICH SECOR: Yes. Yes, there's a couple of these. Actually, I'm told there's five or six of these kinds of communities in the state of Iowa. Opportunity Village is another one in Clear Lake, Iowa. Uh-huh. []

SENATOR WALLMAN: Thank you. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Rich, you...none of this in place yet. []

RICH SECOR: No. []

SENATOR STUTHMAN: So it's just anticipation and trying to get...trying to establish something if there's...and you see there's a need for it, so... []

RICH SECOR: Correct. []

SENATOR STUTHMAN: So but there's nothing in place. You have no record or anything like that yet. []

RICH SECOR: No, there's not. Our plan is to build facilities with private money. However, we would need public money to make the operation work, simply because the caregivers don't have \$4,000 to \$6,000 per month to help support what it's going to take per individual. []

SENATOR STUTHMAN: Are you thinking of just putting something in, you know, in the metropolitan areas, or are you thinking of anything out in the rural part of the state? []

RICH SECOR: As you can imagine, it's a huge undertaking just to get the first operation

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

going. But, yeah, potentially there could be some satellite locations spread across in the rural communities potentially, yes. []

SENATOR STUTHMAN: Okay. Thank you. []

RICH SECOR: You're welcome. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Oh, thank you, Senator Lathrop. What would your budget be as you look at this program? What kind of budget would you anticipate? []

RICH SECOR: Well, it depends upon the number of individuals served and also depends upon what individuals need in the way of services. []

SENATOR HARMS: So let's just take it in general. What...how many people would you want to serve or capable of serving, as you look at this, that would be realistic so I can get a fix on how you would price that out budgetwise. []

RICH SECOR: Well, right now we have a business plan that we're just finalizing and it's kind of a phased approach and the first stage would be to serve 20 individuals. And with serving 20 individuals, I believe our numbers anticipate a monthly cost per individual, about \$6,000 per month. So it's akin to assisted living and/or nursing care for the elderly. As we achieve economies of scale by expanding the village, building more buildings, also increasing the population, there will be economies of scale and there will be some efficiency with regard to being able to spread a lot of the overhead. We think, ultimately, by the time we're serving in excess of 50 people or so, that we think we can get those monthly costs down to probably closer to \$4,500 per month per individual. We don't know how big the village is going to be. We want to start it off small and be able to manage it effectively with the initial 20 people. Someday we'd love to have it as big as

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

many a couple hundred individuals. In Sheldon, Iowa, and in Clear Lake, Iowa, at the Opportunity Village in Clear Lake, I believe they're serving in the neighborhood of a couple hundred people in their various villages. []

SENATOR HARMS: So as you look at maybe 50 people, what kind of staffing would you have? []

RICH SECOR: I don't really recall the allocations offhand, but I would tell you, I think with our 20-person model, I think we've got about a 2 to 1 staffing ratio, I should say 1 staff person per 2 individuals. []

SENATOR HARMS: What educational level will these people have as staff members? []

RICH SECOR: Well, they, obviously, have to have some experience. We don't want to hire anybody that doesn't have experience. There would probably be some kind of a mentor relationship with regard to individuals that would need to be trained. We really haven't worked out the specific hiring practices, the various staff requirements. You know, we've got a business plan that we're finalizing that addresses how potentially we would fund-raise for private dollars to build the initial two or three homes to serve 20 individuals. And I do want to make a point that we anticipate all the real estate, the land acquisition, the construction of buildings and so forth coming from private dollars, perhaps from caregivers, perhaps from foundations, from private individuals. It's the operation dollars that are critical and, as I mentioned before, it appears that caregivers, as a general rule, can only afford maybe about 25 percent of those dollars. []

SENATOR HARMS: I want to go back to your staffing again, because one thing I've at least learned from the Beatrice side is that staffing is critical, and having the right educational level is critical, having the right kinds of staff development is critical. And just to be able to hire people and bring them on, into your system, is not going to work well. So that's why I was asking about the educational level, what your projections are,

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

what type of support are you going to have. Are we talking about doctor's degrees? Are you talking about master's degrees, associate degrees? I mean this is really important to be able to treat the kind of clientele you're talking about, so that's why I'm interested in knowing what you're thinking about in regard to that particular area. []

RICH SECOR: Yeah, we don't, Senator Harms, there's no question we don't want to experiment and, you know, we want to be successful because we don't want to be a disserve. We don't want the program or the project to fail because we want to be able to grow it. And those staffing recommendations certainly are very important and we would certainly implement them. []

SENATOR HARMS: Thank you. []

SENATOR LATHROP: Think that's it. []

RICH SECOR: Okay. []

SENATOR LATHROP: Thanks, Rich. I appreciate your testimony. []

RICH SECOR: Terri, I'll call you up. Thank you. []

TERRI LYNCH: Senator Lathrop and committee, I'm here with my son David, he's a Down syndrome, and with my husband Joseph. I'm present today to really just talk about my situation. David is 35 years old. []

SENATOR LATHROP: Hey, Terri. []

TERRI LYNCH: Yes. []

SENATOR LATHROP: Why don't we have you start with your name for us so... []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

TERRI LYNCH: Oh. Terri Lynch. []

SENATOR LATHROP: Okay. []

TERRI LYNCH: T-e-r-r-i L-y-n-c-h. []

SENATOR LATHROP: Terrific. Thank you. []

TERRI LYNCH: And David is David Luers, L-u-e-r-s. Even though David is 35, he has a mental age of about 2 to 4. I wanted you to see him as a real person, to put a face to the situation. He's not somebody sitting on a shelf, waiting for something to happen. David lives at home with us and we are his guardians. He was born and diagnosed with Down's syndrome at birth. They suggested he could go to the Beatrice home or we could take him home and see how he does. We took him home. He attends the Cass-Sarpy County workshop at...ENCOR's Cass-Sarpy workshop during the day and he does very well. He likes it. He gets on the bus; he rides, unfortunately, a very long period of time, about two hours a day. But he hasn't always had transportation, he hasn't always had services. After...going back to his earlier days, I just want to remark, too, that Nebraska has always been a model and a leader in the early childhood intervention, and he did have early childhood intervention and did quite well when he was in the school system. But I really feel that Nebraska has fallen behind when it comes to serving the adult developmentally disabled citizens. For example, he waited three years for availability to get into a workshop and there was a time where there was not transportation for him. It's not like we lived in the boonies. We lived (laugh) we lived in Bellevue. We were paying approximately \$25 per direction per day and his private transportation exceeded his SSI payment. Now he did finally get transportation and we are extremely grateful for that. But during the three years, of course, he did lose some ground and they need to have a place to go and stimulation. David has been on the waiting list for Medicaid waiver or permanent residential care for approximately ten

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

years, or so I thought it was ten years. And I, you know, Mary mentioned that we were at...we should have been asked when we want him on the Medicaid waiver, when do we want that to happen. I personally do not recall being asked when that should happen. But I did find out, when I talked to his caseworker last month, that he had been bumped off the list. Because I said, where is David on the list? And he said, well, he's not on the list. I said, well, how can that be? You know, I remember this conversation at least ten years ago, maybe even longer. And he said, well, you know, technically David has residential care. And I said, I don't understand. Well, David has his workshop during the day and then he goes to a group home for one to two hours, usually it's about an hour and a half, so that we can work or be able to...I mean, we just can't get him at 3:00 every day, and he said that's residential care. I said, well, I was shocked. How can this be a substitute for 24-hour-a-day permanent living? Why didn't somebody tell me about this technicality? It's a technicality. Is this how the state of Nebraska is reducing the number on the waiting list? This is absurd. Let me tell you about another technicality. David is technically a ward of the state. The state of Nebraska is really not providing David with care and I think the state should be ashamed of this waiting list. Nebraska has been a leader in the past, and it's not. And I don't really want to get into this technicality but just to really emphasize and be clear that the problem is lack of availability, and the availability is related to lack of funding. That's what it boils down to. There are beds out there, there are places, but they're not funded. David is nonverbal so we are his voice. We're interested in Village of Promise because it offers...it offers something we think that would be good for David. []

JOSEPH LYNCH (?): There are many parents in this room. We must make decisions that we believe are good for them. We feel that we are limited in the type of residential care that's available, either in Beatrice State Home or the group homes. We are interested in the new concept for residential care. We do feel that Nebraska Village of Promise would be one that may be the best choice for David and people like him. It's really apparent there's not enough residential care money appropriated for special needs children. We're asking today for consideration for those dollars, that they follow

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

our children to a provider that has a model of care to assist him in reaching his potential in a community-living or assisted-living setting. Most other states have this model of residential care. Why doesn't Nebraska? We're asking you to be open to new, innovative ideas and to appropriate money for people like David. You want me to read it? In the end, if we might be philosophical for a moment, we believe we are judged not only by how many bridges and ball parks we've built but by how we take care of our most vulnerable citizens. Please consider our situation. Please give David and others like him a chance to meet their potential with dignity. Thank you. []

SENATOR LATHROP: Thank you, both, very much. Let me make sure there aren't any questions before we let you get away, Terri. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Terri, from what you've stated, the fact that David had been getting services, was doing very well and then now he's not having a place to go, is that correct? []

TERRI LYNCH: No, he had a gap between the end of high school. He had to wait three years to get day services. And I thought he was on the waiting list for residential care. Apparently this technicality bumped him off. So I asked to be...he be put back on the list and they said, well, that's not possible because he's getting those...that hour, hour and a half between 3:00 and 4:30, and they're calling that his residential care. []

SENATOR STUTHMAN: Which is only a minimum part of what is really needed. []

TERRI LYNCH: Yeah. And that, by him having that hour, hour and a half, we're able to care for him. It was really a bridge to help us while we were waiting for the permanent residential care. []

SENATOR STUTHMAN: Uh-huh. And how...what was the time frame for that, that you've been receiving just this hour, hour and a half? []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

TERRI LYNCH: Just a few years maybe. []

SENATOR STUTHMAN: Just several years. []

TERRI LYNCH: No. No, maybe five. []

SENATOR STUTHMAN: Five years. Okay. Thank you very much. []

TERRI LYNCH: Okay. []

SENATOR STUTHMAN: You had a very good study. []

SENATOR LATHROP: Senator Adams. Oh, I'm sorry, Terri. We're not done with you. []

TERRI LYNCH: Okay. []

SENATOR LATHROP: Just a few more questions. []

SENATOR ADAMS: Terri, you may have already answered... []

TERRI LYNCH: I want to run and hide. (Laugh) []

SENATOR LATHROP: No, you're doing a great job, by the way, and we're glad you're here. []

SENATOR ADAMS: You may have already answered this, but what was David's age when he left high school? []

TERRI LYNCH: Nineteen. []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

SENATOR ADAMS: Okay. So we had that gap between 19 and 21. Okay. Thank you. []

SENATOR LATHROP: I think that's it. Thank you very much for coming down today. []

TERRI LYNCH: Okay. Thank you, Senator Lathrop. []

JOHN HERDZINA: Good afternoon, senators. My name is John Herdzina. I'm from Omaha. And, first of all, I would like to say, and I mean this sincerely, thank you for taking up this issue. I think you've got a real opportunity to make a difference in people's lives. And, man, if I was able to serve on the senate, in the senate, something like this, I'd be fortunate to take up. So thank you for that. I have two children with special needs. I have three children, total. Lived in Omaha my whole life, married to my wife Jacqueline (phonetic), and when my oldest son was born, his name is Grant, it came up before he was born, the diagnosis was terrible, that he was going to have all these problems, mental and physical and everything else. And, you know, we went through the agony of making the decision and said, hey, you know, we believe in this life thing, pro-life, so we had the child. Turns out I had the special needs developmental disabilities. So if you meet this kid today, you know, he's beautiful, 26 years old. He's went through Westside special needs program, special ed program, and in a minute I'll tell you a little bit more about him. But anyway, the doctor is telling us, hey, it was a chance in ten million that that happened. We can't even figure out what it is genetically so don't...it's not going to happen again. Have our second child who I'm proud to say is a...graduated with honors from Creighton University and is employed, doing well. Had the third child and the third child has the same disability as the oldest. She goes through special ed at Westside and this is where...I mean you guys are taking up...excuse me, Senator, you people are taking up such a difficult issue. There's so many things to talk about. I want to try to keep it short and to the point. But, you know, when the Senator Lathrop talked about the transition program when you're 21 and you get out, well, that Individuals with Disabilities Education Act that was mandated by the federal government says, yeah, you've got to

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

do this. So when they're getting all this socialization and education and companionship and care in school, it is a wonderful thing--and I don't know outside of Omaha how good it is but the Omaha school districts and areas do a great job at it--but then when they graduate, it's over. And the problem I'm having when I hear about the list is that, in all our lives, we plan. We like to plan what's ahead of us. I know man plans and God laughs, but I like to plan ahead at what's going to happen to these kids. So I put them on the waiting list for residential well before they got out of school and hoping that they get what they deserve, which is like any, quote, normal person. They have a choice whether they want to go to school, and if they go to school they go away to school and they're independent and they begin to live on their own. My plan for them was just that. They could live with me forever. You know, that's what life is all about. You take care of your own and that's my vocation in life, to take care of these kids. But God forbid I have a heart attack tomorrow. One of the inevitable is going to get me. I'm getting older, sick, disabled, feeble, die. You know, sooner or later they got to go. I just don't see how we let these people exist without planning for where they're going to be. Why should crisis drive where they end up living and who they end up living with? And that's why I'm trying to get across to you that the importance of getting these people off the list is so critical. Without the assistance, they can't...right now they both want to live outside the house. They see their friends living independently. I just can't...I can't afford on my own to pay for them to live independently. Anyway, that...I just...decisions being made by crisis don't make sense to me. Yesterday I found out that I was denied again, because I wanted to move up on what Mary testified to, that priority, getting priority on the registry, so I applied for priority on the registry because Grant has been on this thing for I don't know how many years and just not getting anywhere. So we had made out the application and everything, caseworker called me yesterday and said, you've been denied. I said, well, why, other than there's no money, the standard answer? And he said, well, because they aren't being abused and there's no crisis here to where they're in imminent danger. I said, well, of course not. You know, they're with my wife and I. But what basis is that to turn them down? They said, well, under the way the rules are now with the list, it's ruled by crisis, not by...and I forget the terminology Mary used with you

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

all about having a date certain down the road, date of choice. And he said, there is no such thing right now, so it's all by crisis. Well, again, I think that says it, in and of itself, what the real problem is. You know, it's kind of like this Safe Haven Act we have is kind of where we are. People with children under 19, this act, you know, they drop this person off and the state has got to take care of them. Well, I told that to my caseworker. I said, well, what if I just said I threw Grant and my daughter Gabriel out; she's your problem? And he laughed, he says, well, one, you're not going to do that and, two, if that happens I'll deal with it. So that's the severity of the situation, senators. I know this funding is a huge issue. Thank goodness we now have a surplus. But that money really is needed to take care of these folks on this list. And Senator Lathrop brings up an excellent point about whether or not there's more coming on as there are going off, and that's a tough, tough issue to deal with. But that's really all I have. I think I got the point across. []

SENATOR LATHROP: Thanks, John. We'll see if there's questions. Can you tell us how long Grant has been on the list, John? []

JOHN HERDZINA: Well, he graduated. He's 26. He's been on the list probably three years before but, you know, he...so he wouldn't be able to have lived outside the house until after he graduated. So I'd say effectively over five. []

SENATOR LATHROP: Five years. And what you're being told is, unless he becomes a priority one by essentially being abandoned, you're on the list perpetually. []

JOHN HERDZINA: Yeah, he's not going to live anywhere else. And I have appealed that and it will come up here to the Health and Human Services people but, you know, I've been told already that I'm not going to get anywhere. And I submitted...I had them both tested with the psychiatrist and the psychiatrist wrote letters to the coordinator and the supervisors and said, hey, these people need to be on their own, you know? They have some mental capability there and they want to be independent, and in order for

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

them to mature and nurture and be a benefit to society they need to be out there. But it didn't do any good. []

SENATOR LATHROP: Okay. Thank you very much for your testimony. []

JOHN HERDZINA: Thank you all very much. Appreciate it. []

JEANNE PATRICK: Thank you, Senator Lathrop and all of you. My name is Jeanne Patrick, P-a-t-r-i-c-k, and I come here as a grandmother, speaking for my grandson Justin. Justin is 19 years old. He also graduated from Westside. I reminisce back through his younger years, he had really good social contacts and services provided and was relatively a happy, happy young man. He's severely impaired. He's in a wheelchair. He has to be dressed every morning. He has to be bathed. He can dress...he can go on and off of the toilet in a fashion, and feed himself a cheeseburger and fries, but he is very impaired. But intellectually and mentally, he's not challenged. He's an intelligent, bright young man. He's also very depressed. He's...all the years he's gone through school he was with his peers, very well accepted at Westside. You know, I couldn't have asked for a better school district. They actually moved from another school district because of the money available at Westside. But...and my son went out of the work he was in, doing his self-employment, so he could be available after school. I'm also self-employed so I, throughout the years when Justin was young, many times we were scurrying to meet the bus at 3:00. None of us were working our regular schedules so we, more than all of us, you know, tried to give Justin the best life that he could possibly have. There are two other grandchildren. They're in their teens. They have put forth a valiant effort. We've all given our best to Justin and the best that we could possibly have for him. But here we are. You know, we're out of high school and, like Mr. Herdzina, there's nowhere to go. There's a real, real gap. And when he says, Grandma, you know, well, it used to just bother me when he'd say, Grandma, am I going to always be a wheelchair boy? Well, if that doesn't get your heart, nothing does. You know, (inaudible) Justin, walking isn't the most important thing in the world. You

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

have something to give the world and you're going to...you know, you're going to be just fine. But when he asks you, Grandma, where am I going to go? What am I going to do? And there's no transportation for him to go to college. I believe before they used to pay for college, but now with the Disabilities Act that was taken away. This is what my daughter-in-law told me. I'm not sure if that's valid, but I think it is. It's been a huge financial strain on my son and daughter-in-law. They both are hard workers. Everybody pitches in. You know, both...all the other...the other two grandsons are just very, you know, very good in school sports and excel. They all just kind would do the best, you know, that we possibly can, but we still have this void for Justin. And physical therapy was there for him, although the insurance only covers so much of it. Shriners was there for him. I can't tell you...and we know we're fortunate. He can't walk and he can't do fine motor things. We're very fortunate because there's so many other more severe disabilities than Justin's, even though he's very, very handicapped. You know, whether it be his eye glasses or an insert for his wheelchair that's \$1,000, you know, I've kind of had to be there. They don't have the money. The insurance doesn't cover all this. The funds aren't there. And again, Justin is kind of...he's in the gap and his friends are driving. They're off to college. He wants to go to college. Finally, Munroe-Meyer now will provide transportation one day to Metro Tech. He is so excited, because these other funds have not been there for him. Munroe-Meyer has been wonderful. I contribute there. The family contributes there. But for his summer camp, I believe it's \$350 a week in the summer. How many families...you know, I think Justin goes two or three weeks in the summer, but that's a lot of money to a family with three teenagers and, you know, two that will be soon going off to college. I don't know how much more my...I just don't know how much more my son and daughter-in-law, you know, I just don't know how much more they, you know, they can endure. He just had surgery for a hiatal hernia. It set him back four months. And then he didn't have his physical therapy during that period so now we've got to maintain and try to get that recovered. But my ray of hope for Justin and these other young disabled adults like him is if there will be a Village of Promise, or a facility where these...they can have their peers. They maybe might work there. Maybe they'll work somewhere else. But most...some of them are employable.

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

They tell Justin he's unemployable. I know he could be. He's very personable. He could be a dispatcher. He could be a greeter. And I know other...15 other friends of his that have a potential of being employed but they're kind of in the gap too. So I'm just here on his behalf and all of his friends that I have met through the years, as I've been there for him. I'm going to be there for him. He can't wait till I retire because I'm hoping I can find a business that, if that's what I have to do when I retire, is be there for him. So I do hope this funding, whether it's the Village of Promise or another facility, or whether it's for transportation, or schooling, or special therapy, these young adults are lost and they need us and they need us now. And I'm sure the list goes on. []

SENATOR LATHROP: Thank you. Senator Stuthman looks like he has a question for you. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Jeanne, first of all, I want to thank you for your testimony and I want to thank all of those that have come here. We really appreciate the fact, you know, of hearing from people that are in a situation and are looking for something to help. I just...it's more of a comment. I think the best gift for you, as a grandmother, would be that your grandson could find an employment and a social environment for him to be in. []

JEANNE PATRICK: I know. He wants to live independently though. He would like to, you know, he's got two or three friends that probably he could do that with, but they still have to have someone to assist them wherever they would reside. And they don't have the funds to provide that, you know? []

SENATOR STUTHMAN: And all you're asking is just a little bit of a help so that he could accomplish that. []

JEANNE PATRICK: I think the funding is obvious for all these needs, for all of these needs. []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

SENATOR STUTHMAN: So thank you very much for your testimony. []

JEANNE PATRICK: Thank you. []

SENATOR LATHROP: Thank you. []

LARRY CARTER: Good afternoon, senators. My name is Larry Carter. I've lived in Omaha for 15 years now. I have a 20-year-old son Jeff with...diagnosed at birth with mild cerebral palsy and significant cognitive disabilities. I'm actually one of the lucky ones. He has virtually no health/physical issues, other than a seizure disorder which is pretty much under control with medication. Mentally, he functions at probably about a second or third grader. He's never going to hold a competitive job, but he is certainly capable of doing things other than sitting in a workshop and putting things in bags and different things like that. He has a wonderful personality. He has no behavioral issues to speak of at all. He's very easily redirected, smiles, talks all the time, matter of fact talks too much (laugh) at times. I've been his primary caregiver. I retired. Fortunately, financially I was in a position where I was able to retire when he was 16 and my wife and I thought, as a male, that he needed my presence more as a caregiver. My wife has continued to work. It's a sustainable situation for the foreseeable future. But when I look at my son Jeff, he deserves the same ability and opportunity that any other citizen of the state of Nebraska does. He wants to live on his own, but he needs some assistance. He doesn't need 24-hour care, but he needs somebody to check up on him. He needs to be in an environment where he's with his peers. That's how he's going to develop. If you would have seen him when he went into school and what he's come out, it's just been a world of difference. I will echo a couple of comments that some other speakers have said. The Millard...we've been in the Millard school system basically since I think he was in third grade when we moved here. He has developed from both a maturity, an intellectual, although understanding that he's severely limited in that, communication skills, and if I can't find an avenue to get him into an environment with his peers, he's

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

never going to...he's not going to develop any more, as good a relationship as he and I have, that's not fair to him that he's going to be living with me and my...and that. Because he's in an environment, he almost becomes in a cocoon when he lives there because he doesn't have his peers and we have limit...you know, we interact. What he and I...we're able to interact. We love to watch football together, we watch sports, but there's just...there's a limitation on what a 56-year-old male and his mother, how they can interact with a 21-year-old male. So it's imperative that for people like my...and, as I said, I'm the lucky one of a lot of these parents because I don't have to deal with some of the severe physical, behavioral and mental issues that come along and it is still a challenge and a very difficult thing to deal with. And I just urge you, these people, they deserve the opportunity that everybody else does. Thank you. []

SENATOR LATHROP: Thank you. Any questions? I don't see any. Thanks for coming down. I very much appreciate your testimony. []

RICH SECOR: I'm Rich Secor again. Just want to talk to you a little bit about my son for a minute or two. He doesn't talk. He has to be reminded to go to the bathroom. He overstuffs when he eats. He needs assistance to dress, wash his face, bathe, brush his teeth. He cannot cross the street without supervision. He cannot be left alone. He runs into things because he's awkward and because he has an abnormal separation of a C-1 and C-2 vertebrae in his neck. Consequently, he looks down when he walks and runs. He has the same intellectual capacity as a three-year-old. He has Down's syndrome. He picks at himself, making his fingernails and toenails bleed. He's very compulsive. He makes only superficial eye contact when he's spoken to. He will read a phone book and his way of reading a phone book is to flip every page, page after page, after page, minute, hour after hour. He's compulsive. He's also autistic. So my son has a dual diagnosis of Down's syndrome and he's also autistic. He's 15 years old. My wife and I just placed him on the waiting list in July, anticipation that when he's 21 we're hopeful that he'll be able to get services and there will be funding available. I just want to echo what Larry said and others have said up here. It's a...this is all about not Village of

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

Promise. It's all about our concern about the availability of funds to serve the needs for adults with cognitive disabilities. And I think I want to stress, too, this isn't all about parents or caregivers having respite in the long term. It's all about enabling these individuals to maximize their potential. These individuals want to live away from home and they want to have these services, and it's important to recognize it's all about them. It's not about us as caregivers. Thank you very much and I appreciate the opportunity to make this testimony. []

SENATOR LATHROP: Thanks, Rich. I think Senator Wallman has a question for you. []

SENATOR WALLMAN: Yeah, thanks for coming, Robert (sic). As you looked at this list, I'm sure you did, how many is on there and all this, do you have a preference? Would it be community-based or an institution like BSDC where your son could go to or...? []

RICH SECOR: Well, I mean I have...I have a preference that he would end up in a village like a community like what we're planning which would have separate residential homes, would have caregivers living in the homes to watch after him. That there would be employment on that campus, such as maybe dog grooming, maybe there will be a retail shop, that kind of thing. There would be education opportunities for him to advance his education. There would be recreation opportunities, maybe a gymnasium, that kind of thing. []

SENATOR WALLMAN: Northwest Villages has a lot of this stuff, as you realize, in Iowa, but you can...if you have so much ability then you graduate out of there. You know what I mean? They will not literally take you forever. []

RICH SECOR: Right. Yeah, I think, yeah, I think that's a great point, Senator Wallman, that you make that I think any of these planned communities, whether it's group homes or a village concept, I think the idea is to try to maximize the independence of these individuals. And if they could eventually live on their own, I think you're right, I think they,

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

quote, graduate and let's get them mainstreamed. []

SENATOR WALLMAN: Well, thank you for coming. []

RICH SECOR: Thank you. []

SENATOR LATHROP: Thanks, Rich. []

JASON TONJES: Senators and Chairman Lathrop, my name is Jason Tonjes, that's T-o-n-j-e-s. I came here today, I have a three-year-old daughter with Down's syndrome. I became aware of this issue probably sooner than most. I have known Rich for quite awhile and several months after she was born he asked me to come and join and listen to the few at the Village of Promise committee meetings. And through that, I, you know, learned that there's a problem out here. You know, I don't have a lifetime of stories and experiences like many of these people do, but I also don't want...don't really want to go through that for the next 20-25 years. I don't want to be back up here when my daughter is 25 having the same meeting. You know, it's something, I guess for my own benefit, my daughter's benefit and our ability to plan for her future, it would be nice to see something start happening within the state within the next few years. I do...you know, she just started with the Omaha Public School system this year. From what I've seen so far, the support there is tremendous. She's advanced considerably in her two months through the preschool. But I, you know, I continue to hear the stories of what happens after they're 21, and that concerns my wife and I. You know, I want her to have a place where she can live, she can be independent, do the things that the other kids do. I look at it now and they're a kid and they're happy and everything is carefree, and I'd like to see her be able to enjoy that when she hits her adult years. So I guess what I've really learned in the last few years, and I really encourage the state to do it, is, you know, to look at some alternatives. I mean, the village concept, which I do like, that might not be the alternative. We need to look at some cost-effective alternatives. We need to handle the staffing issues. I heard the gentleman from the Teamsters earlier today talking about

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

the staffing issues. I actually have some experience as a...I'm a CPA by profession and I've done some auditing of one of the state's larger providers of these services and, you know, I always...I was told, you know, that they could potentially take on more people but the problem would be finding, you know, or affording people to care for them. At some of the rates that the individuals were being paid, the turnover was just too great and it became a difficult burden on the executive director and some of the key managers. So I don't have a lot to say, I don't have a lot of experiences. You know, I am concerned for the future. I really just want the state to maybe look for other alternatives and hopefully cost-effective ones. Thank you. []

SENATOR LATHROP: Very good. Thanks, Jason. I appreciate your testimony today. []

HAL LANKFORD: I'm Hal Lankford. My wife Elizabeth and I live in Omaha. We have a 49-year-old son with Williams syndrome who resides on the Mosaic campus in Beatrice. We've been so fortunate, I almost guilty...feel guilty sitting here. When he...we put him on a waiting list in Omaha when he was 18 with ENCOR. When he turned 21, of course, the program, there was nothing available, so we went to the cupboard and they had lost the list. So someone told us about the Martin Luther Home in Beatrice and we were so lucky to get him in there. It is a fantastic place. And the way this testimony ties into the waiting list is that I'm afraid that underfunding of that institution is going to lead to a longer waiting list. But I'll get to that in just a second. We, you know, it's a long ways from Omaha down to Beatrice, when you go down there every ten days or two weeks or something, and we're obviously aging so we wanted to find a place closer to Omaha or closer to our kids, Milwaukee and Chicago. So we looked at places in Wisconsin, Illinois, Iowa. We always come back to Martin Luther Home, now Mosaic. It's the best place that we have found for him. I think that apparently the folks in Health and Human Services don't eat or they don't drive cars. Their proposed budget raise for the ICF/MR down there is 1 percent. That's really going backwards. And they won't permit a salary competitive. It's, I think, \$8 and something. They allow \$10 and something for BSDC, and it's hard enough to find somebody at \$10 an hour. When you're behind the curve

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

with \$8, they...last month they had 18 vacancies. So I don't know, these people aren't necessarily obligated to provide this service to the state of Nebraska. We're fortunate they do. We'd have a heck of a lock bigger problem if we didn't have Mosaic providing these services. And I want to add my statement that we really appreciate your dedication and I have heard that you don't even get time and a half for this work.
(Laughter) []

SENATOR LATHROP: That is true. (Laughter) I'll see if there's any questions. I don't see any but we...oh, I'm sorry, Senator Wallman does have a question for you. []

SENATOR WALLMAN: Thank you for coming. Mosaic is in my district, as you well know. []

HAL LANKFORD: Yes, it is. []

SENATOR WALLMAN: And I agree with you, we have to find better funding for employees there. And I'm glad you're happy with them, but I do know they have a quality control person, goes around to different states. I know that individual and she checks up on the institutions and much tighter control probably than we have in our own state. So thank you. []

SENATOR LATHROP: Thank you very much. We appreciate your testimony today. []

HAL LANKFORD: Thank you. []

SENATOR LATHROP: Are there any...yes. How many other people are interested in testifying today? Okay, one, two other hands. Good. []

GAYLE WIDICKER: Hello, my name is Gayle Widicker, G-a-y-l-e W-i-d-i-c-k-e-r. I just was here today to listen. I was originally from Nebraska. I graduated from UNL with a

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

special ed degree in 1974. I married, moved to North Dakota. Now, because of a divorce, I have returned to Lincoln. I brought my special needs daughter with me. She is 24 years old. I am shocked and surprised at what I ran into when I returned with her. When I applied for DD services and was told there would be five years, ten years at most for her to get day services. I was told I'll never see residential services because she's got a mommy that loves her. So what I have been...what I've been up against is all the parents telling me, Gayle, have you bought your house yet in Lincoln? I said, no. Then don't. Leave the state. It's been recommended I go to Iowa, I return to North Dakota. It surprises very many people that North Dakota is on the cutting edge. When I left Lincoln with school, we were on the cutting edge. For me to return to Nebraska and see where the state is at on this is heartbreaking and it's heartbreaking that my state of Nebraska, my home state, people are telling me to move away. This is what I am faced with right now. When I returned here, I had BlueCross BlueShield of North Dakota. BlueCross BlueShield of Nebraska denied me, so I need to find employment. My daughter was diagnosed with a brain lesion. Because of this, she has some cognitive disability, minor motor disability, but a severe seizure disorder that is noncontrolled by medication. She pretty much needs 24/7, some type of care because of the seizures. On Tuesday, she went through ten grand mal seizures. This is on the medication that is state of the art that I've been through everywhere. So right now I've been in Lincoln now for 11 months. I have 24/7 care of my daughter and am unable to find a job to cover my insurance. Now Lindsey (phonetic) went through the transition program at the schools in North Dakota. She did very well. Once I came down here and found out we were not going to get services to maintain her skills that she did have, we volunteered at the Tabitha Nursing Home two to three times a week. She would...there's a lot of things she could do, but she does, because of the seizure disorder, she has simple complex, complex partial, and atonic clonic seizures. So she would need job-supported services and she would need transportation of some kind. Even putting her on a bus would be very risky. Right now the divorce is...we are in the middle of the divorce and it looks like I'm going to be forced to return to North Dakota, where all my family is in Nebraska, his family is in North Dakota. But so we are forced to leave, and I think you need to know

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

that. Your parents are telling new parents to leave the state because of the situation of your developmental disabilities in Nebraska. I think that's very sad and I think it's very poor advertising for your state, our state, it's mine. I mean, I'm back here and I had intended to buy a home, live here and my retirement here. I guess that's all I have to say. []

SENATOR LATHROP: Thank you very much for that testimony. Senator Stuthman has a question for you. []

GAYLE WIDICKER: Yes. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Gayle, what type of service were you getting in North Dakota then... []

GAYLE WIDICKER: Okay. At the... []

SENATOR STUTHMAN: ...or give me the difference between what you were getting there and what you can't get here. []

GAYLE WIDICKER: Okay. I will clarify this. We were on a farm and, after graduating at 21, she was not ready to go into services. And then, you know, they're talking about catastrophic things happening, whether or not they die or they become ill. They are not figuring in the factor of a divorce that puts you in another different situation. Because my son and my husband and I were taking care of her predominantly on the farm. She was just getting ready to go into services when this happened. In North Dakota, she would have an apartment with supported work services. She would have a direct service provider that would take her to work, be on the job with her, return her to the apartment. The apartment has, oh, she would probably be mostly alone in the apartment, but there would be a two-way, I don't know, intercom system so that the provider of the apartment, the person that's always on duty within the apartment, would know if she had

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

a seizure and could assist her. There would be assistance in fixing food, cleaning, anything, depending on the amount of assistance she would require. []

SENATOR STUTHMAN: And she could have...could have received those services, you know, almost immediately after she... []

GAYLE WIDICKER: Immediately. []

SENATOR STUTHMAN: ...graduated out of school. []

GAYLE WIDICKER: Immediately, yes. []

SENATOR STUTHMAN: There was no waiting period there or anything. []

GAYLE WIDICKER: No waiting list. When I talked to North Dakota, they were shocked you were still using a wait...that you had a waiting list in Nebraska. They did not think...they were just shocked. They were very sorry to hear that. I have looked into Iowa, because I've been told your family is all in Nebraska, go across the river. Iowa does not have...there are only a few counties that have...I think there were four counties maybe that had a waiting list. []

SENATOR STUTHMAN: And before you came back did you realize there was a waiting list here? []

GAYLE WIDICKER: No, I did not. When I left Nebraska I... []

SENATOR STUTHMAN: I mean when you left North Dakota. []

GAYLE WIDICKER: No, I did not. I would have never dreamed that North Dakota was in...the state was in this predicament because of the way it was when I left. You were

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

cutting edge when I left. I expected it to be the same. That was my mistake. I had a lot of faith. In fact, many of my friends were so tickled that I was coming back here, that there would be better facilities for Lindsey (phonetic) down here, because they were bigger, they would have more opportunities, more people with her...that function on her level. Because North Dakota is very rural and we were in rural North Dakota, and so everybody was, you know...but the facilities were wonderful. []

SENATOR STUTHMAN: Yeah. Well,... []

GAYLE WIDICKER: But...and I do want to...I've had people say, well, Gayle, that's nice that you want to return here, but, you know, you've paid all your taxes in North Dakota. We own property in Lincoln. We have paid income tax in Nebraska for 30 years. We have paid property taxes in Lincoln for 30 years. I am not one of these that's just looking around for the best place, for the best services, which state do I go to, but I've been told not to come to Nebraska and I find that highly embarrassing. []

SENATOR STUTHMAN: Well, thank you, Gayle. Thank you for your testimony. []

SENATOR LATHROP: Think that's it. Thank you very much for coming down today. We appreciate it. []

KATHY HOELL: Good afternoon. My name is Kathy Hoell, H-o-e-l-l, and actually when I came today I was not going to testify, but I decided this is probably one of the best chances I'm going to get to say what I need to say. One, I am on the LR156 board group. We have looked at this waiting list repeatedly over the years. There have been recommendations already made for this waiting list that we have never implemented. Mary Gordon's group contracted with Senator Byars and Deb Weston of the Arc and they did a study with recommendations for addressing the waiting list. This was a couple of years ago. It was never implemented. And I'm going to tell you exactly what I told the group (inaudible) waiting list. The disability...I know your charge is only

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

developmental disability, but the fact of the matter is the disability system in Nebraska is broken and just fixing pieces and parts is not going to make (inaudible). We have the DD waiting list. They've changed the name in Behavioral Health. (Inaudible) he's changed the list to not a waiting list. We have people with disabilities who are not getting the services they need. One of the parents talked about employment. One of the key pieces of legislation that we have been trying to push through the Medicaid Reform Council is the Medicaid buy-in which would allow people with disabilities to go to work and to still have...still keep the supports and services they need because the fact of the matter is most private insurances aren't going to cover them because of preexisting conditions. Another problem with our system, we have...whether it's transportation, respite or whatever it is, you have to use these approved providers. You're paying \$25 for a one-way trip. But guess what. What other states do is you can get a person, whether it's a neighbor or a nonresponsible family member, to provide the same transportation or respite service for like \$10 bucks an hour. It's cheaper. It's more cost-effective. The state of Nebraska is paying so much for the management at HHS that we are cutting back on disability services across the state, whether it's in Columbus, whether it's in Omaha. No matter where it is, we're doing a really big disserve to these people. People with disabilities have the same hopes and dreams as anybody else and we're just not letting it happen. The best thing the state could do is to basically trash the entire disabilities system, the silos, (inaudible) chances divide into and create a unitary, one single disabilities system, whether you have a developmental disability, whether you have a behavioral health disability, or if you have a physical disability. The choice is yours. You have one place to go to, one place to get services, no waiting list of disability. Everybody that's on the waiting list has already been deemed eligible. We need to provide them with an entitlement that if you are declared disabled by whatever system they choose, you get services. We don't put people on (inaudible). Waiting lists are archaic, barbaric. We've got people out there who are 76 years old trying to figure out how, if they have a heart attack tomorrow, what is going to happen to their son or daughter. That is not fair to them and it's not fair to the person with a disability. I'm just getting over laryngitis too. (Laugh) Our system is just...I have lived

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

(inaudible) United States and I have been involved with disability for 25 years on a national level, and I have never seen anything as convoluted as I have in Nebraska. This is (inaudible) just does not make sense. Now all the Village of Promise, I see that probably as just another form of an institution, but I'm not even going to go there, whether I agree with it or not, because I understand where these people are coming from. They want some place where their children can get the supports and services they need, and if it means building a Village of Promise or whatever, that's the only way they can do it. Maybe that's what has to happen. But I think the Legislature has a responsibility to its most vulnerable citizens and step up to the plate and provide them with the services and supports that they need. Thank you. []

SENATOR LATHROP: Thank you, Kathy. We appreciate your testimony, your monitoring this commission, and your appearance once again. I don't think we have any questions for you, so thank you again. I think there was a hand or two that was left. Yeah, come on up. []

TAMMY WESTFALL: I promise to be brief. []

SENATOR LATHROP: You're fine. You're fine. []

TAMMY WESTFALL: (Exhibit 2) Senator Lathrop and members of the committee, my name is Tammy Westfall and I gave brief testimony last month and I just want to do a quick follow-up in regards to the testimony that I gave last month. I am the regional vice president for Nebraska services. The Lankfords were up here earlier and had told you about the budget, the biennium budget that has requested 1 percent increase of funding, and I just wanted to reiterate that that basically means for our three ICFs approximately \$200,000. Eighty percent of that...or \$80,000 of that would be the cost to the state. The 60 percent, other 60 percent, would be the cost to the federal government. So that's \$80,000 (laugh) for the biennium that has been requested for three ICF facilities for 245 people. So I just kind of wanted to put that out there in

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

perspective. So as far as wage increases, increasing starting wage, you know, benefits, that's just not going to cover it. The only other thing I want to say today is that I wanted to let you know that back in July 8 Mosaic submitted a proposal to HHS to operate some small ICF facilities throughout where Mosaic currently provides services. We submitted a complete proposal and this would be to assist in the transitioning of BSDC, folks from our own ICF facilities into the community, nursing homes. But I just wanted to let you know that. We currently operate several small ICF settings in other Mosaic states where we operate, and that's in Texas, Indiana, and Iowa, and then, as you well know, we have the small nine-bed facility in Grand Island. Just want to say, in ending, is that we again are willing to partner with the state in assisting in any way that we can and that's really all I have to say today. []

SENATOR LATHROP: I think you're going to get some questions... []

TAMMY WESTFALL: Okay. []

SENATOR LATHROP: ...and beginning with Senator Wallman. []

TAMMY WESTFALL: Okay. []

SENATOR WALLMAN: Yeah, thanks for being here, Julie (sic). I'm going to ask you just a point, but I'm pretty blunt. Do you think Mosaic could run that institution better than it's being run? []

TAMMY WESTFALL: I would not...I would not comment on that. I do feel that Mosaic provides good services... []

SENATOR WALLMAN: Oh, I do too. []

TAMMY WESTFALL: ...but I just...I wouldn't comment on that. []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

SENATOR WALLMAN: Okay. []

SENATOR LATHROP: No other questions. Thank you very much for your testimony. []

TAMMY WESTFALL: All right. Thank you. []

ALAN ZAVODNY: (Exhibit 3) I was going to have to get mad at Tammy if she made you mad right before I came up. Senator Lathrop, members of the committee, my name is Alan Zavodny, A-l-a-n Z-a-v-o-d-n-y, and I'm the chief executive officer of NorthStar Services and current president of the Nebraska Association of Service Providers, and recommending other community-based providers. And we didn't want to let the waiting list testimony go by today without offering the issues that we feel will help you as you prepare your final report, that what the providers would need to make this work. And our three priorities are, to make this viable: reimbursement rates at reasonable amounts to cover costs; a person-centered funding system based on need, not available resources, at any given point of time; and finally, flexibility in funding, not constrained to a month-to-month reconciliation, a small emergency fund that covers special circumstances as they arise and people's needs change, and approve a funding level and not just adjust it down in six months, and we'd like to see funding based on outcomes as opposed to habilitation that we talked about earlier. It is our hope that you will see fit to include in your final report that community-based salaries should be funded at 100 percent of a Tech II salary. It would be helpful to set that amount about 10 percent above the starting wage for the Tech II to give us the ability to give raises, but we'd be happy with getting to the Tech II level at this point. And that's all I have. []

SENATOR LATHROP: Alan, right now are the folks that provide services in the community-based settings, their pay is tied to what we're paying a tech down at Beatrice? []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

ALAN ZAVODNY: The Tech I, which they don't hire at, and it's 90 percent of that. []

SENATOR LATHROP: So it's 90 percent of the lowest level... []

ALAN ZAVODNY: That exists. []

SENATOR LATHROP: ...of a care provider, direct care provider, at Beatrice? []

ALAN ZAVODNY: That is correct. []

SENATOR LATHROP: And so what's that right now? []

ALAN ZAVODNY: Oh, that's a good question. I'd hate to guess but last time I remember checking it was around \$9.38, but don't hold me to that. I will get that... []

SENATOR LATHROP: Is the \$9.38 what they're paying for somebody in Beatrice, or is that 90 percent of it or what you're funded at? []

ALAN ZAVODNY: We...\$9.38 was the Tech I starting. it was right around there last time I checked, and we get 90 percent of that. []

SENATOR LATHROP: So you're under. You're \$8-something an hour? []

ALAN ZAVODNY: Yeah, our starting wage in NorthStar is right around \$9 an hour. We are actually paying more than we're funded for, but we take it from operating. Because it would scare you the quality of people you get for under \$9 an hour. It scares me. []

SENATOR LATHROP: Yeah. They're not...yeah, okay. []

ALAN ZAVODNY: Keeps me awake at night sometimes. []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

SENATOR LATHROP: Are you mostly up in northeast Nebraska? Do I remember that?
[]

ALAN ZAVODNY: Twenty-two counties in northeast Nebraska. []

SENATOR LATHROP: Okay. I think that's all I had. I don't see any other questions. []

ALAN ZAVODNY: Thanks. []

SENATOR LATHROP: So thanks again for coming back. []

ALAN ZAVODNY: Uh-huh. []

PATRICK BOND: Thank you, Senator Lathrop and senators. I'm not...my name is Patrick Bond, B-o-n-d. I'm not part of any committee, any special group. I'm actually a parent of an angel and my angel's name is Christian (phonetic) Bond. He was diagnosed with a condition called periventricular cystic inflamatia (phonetic), and basically it can be misdiagnosed as autism, but he can grow out of it with the right promptings, unlike autism. The reason I come to you today, and I came at the request of the president of the Madonna School in Omaha, Sister Michelle Faltus, to be a support. But as I sat here, I became evident I have to make known what we go through, and my son is only eight years old. When he was diagnosed, we were told he'd be put on the waiting list. When I contacted about the waiting list what I was told was don't put yourself on the waiting list, it's not going to happen. When he went into OPS, I was told the same thing--don't do on the waiting list, it's...nothing is going to happen, it's too big. When we pulled him out of OPS because OPS wasn't providing what he needed and personally funding his education at Madonna School...and you'll have to bear with me. I'm not a public speaker so I'm kind of shaking. []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

SENATOR LATHROP: You're doing fine. You're doing fine. []

PATRICK BOND: When we did that what I was informed by many people was, as another person had said, get out of Omaha, get out of Nebraska, and my response was, well, we've got him in Madonna, he is doing so well. They said, that's fine, Madonna has a wonderful program that will get these students to a point when they graduate, but there's nothing afterwards; you'll be on a waiting list, leave the state. And it scares me because I have an eight-year-old who dreams of having a job, and it's not a job in computers. His dream is to be a Wal-Mart greeter. He's not going to be able to get that because there's not going to be that kind of support. If you look at my son, he looks like any other child. You watch him run; you know there's a problem. He's a very loving child. He's a very deep-feeling child. And it scares me to see the waiting list as it is. And when I went last week to actually sign him up on it, I was told you're looking at 15 to 20 years past when he turned 21. And I at that point said, well, we will figure different aspects. But to look at what's going on and to see my son with the idea of just being a greeter but not being...and knowing that there's not going to be that kind of support at that time, I mean, I'm not a very wealthy individual at all. I drive a truck for a living. But when it comes down to these people, you need to ask yourself, when you graduated high school, when you turned 21, each one of you decided which road you were going to take and you had the ability or was given the ability to make that happen. My son, at age eight, has an idea of the road he wants to take but has not the ability and, as the way the law stands right now, has not the support to make that happen. Thank you. []

SENATOR LATHROP: Thank you very much, Mr. Bond. That was well put. I don't see that we have any questions, but we do appreciate your testimony today. []

PATRICK BOND: Thank you for your time. []

SENATOR LATHROP: Yep, you can place it in the box and make yourself comfortable.
[]

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

ELIZABETH LANKFORD: I didn't intend to talk but you can't really keep me quiet. I'm the other half of the couple that have a son in the Mosaic campus in Beatrice, and I just wanted to say that... []

SENATOR LATHROP: Ma'am, can we have you give us your name so we can make a record out of... []

ELIZABETH LANKFORD: Oh! Elizabeth. Elizabeth Lankford. []

SENATOR LATHROP: Okay. Great. []

ELIZABETH LANKFORD: Okay. And I just wanted to say that the kind of people they have down there, the staff that they have, are so dedicated and we...they're not going to live forever and we want to keep staff there that are as dedicated as they are, and they do need more dollars. And anyhow, the type of thing, I brought this--my husband says, oh, you shouldn't do that, but I did. This is our son. He was diagnosed as severely to moderately mentally retarded after he was a few months old and he has Williams syndrome, so he has a gift of music and he's able to play by ear. He just taught himself and plays for them. And this is a staff member that, during their chapel service, sits with...sat with him and would ask him to play certain things with him and he would play along. They take extra care. They do extra things. And that's why I think the Village of Promise here in Omaha is going to be the same type of place. I really hope they get this off the ground because it does have a lot of promise. Thank you. []

SENATOR LATHROP: Thank you. Dan, are you getting out of your chair? []

DAN MALONE: Just for a second. Senator Lathrop and committee members, my name is Dan Malone and I just want to share a quick thought with you. I relocated back to Nebraska some time ago and I have a special needs son who will always have to have

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

an infrastructure around him. There's no question about that. I read in the paper one day where the...a senator here at the Legislature had introduced a bill, and it passed overwhelmingly, to provide a \$6.5 million grant to real estate developers that could provide housing for disabled citizens of Nebraska. Sounded like a noble plan to me and, being new to Nebraska, I called up here to Lincoln and asked for that senator's office and asked his secretary to send me a copy of the bill and any comments from the committee and whatever I could learn about it, and it didn't come. And so I waited a week or so and called again, and again it didn't come. And so, being genetically challenged and Irish, I called and asked for the senator himself and I was...got his assistant and I explained my search here and she said, well, Mr. Malone, I should tell you, yes, the body approved that voice vote but, if you'll notice, it's for a fiscal year two years from now, and next year it will be pushed off again and by the time it comes up it will be gone; it's not going to happen. I thought, wow, that's an interesting discussion. And I wanted you to know that discussion was 20 years ago. My son is now where he's looking for housing. He also needs to get on the waiting list. I'm kind of a right brain thinker. If you take the people that got off the list and divided it into the number of people on the list, I'll know why I'm on the list, okay? So I just want you to know there's a lot of voiceless people out there. I appreciate you listening to these discussions today. The housing is the big deal. And before I shuffle off this world I'd like to make certain that he's not a candidate to fall through the cracks. And I'm going to leave you with this last chilling thought. It's chilling to me, as a dad. He's a big boy, got hearing disabilities, can't hear anything, got eight brothers and sisters. If somebody would push him or he thinks they're making fun of him do I think he'd smack them? Yeah, I do. He hasn't, but I...and he goes to Madonna School too. He's a good kid but if in another environment, three years from today, four years from today, could he do that? I asked a social worker who's familiar with these people--what happens to him if I'm not here and he hits somebody? And he's nonverbal, can't speak. Oh, he'll be up at Immanuel Hospital, he'll be in a locked unit; they'll have more drugs in this kid than you can imagine, and if he's not responsive and they can't find a cure plan and they can't find a housing environment, he goes to Beatrice State Home. Now that's almost a chilling end to a bad

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

mystery movie for a dad, and I just want you guys to think about that as you drive home today, that these are kids that are sitting around, waiting for some response, and I hope that doesn't take another 20 years. []

SENATOR LATHROP: Thanks, Dan. Wait a minute. We got some questions. []

DAN MALONE: Yes. []

SENATOR STUTHMAN: Dan, I have one comment. []

DAN MALONE: Sure. []

SENATOR STUTHMAN: When you was talking about, you know, that bill that was introduced and stuff like that... []

DAN MALONE: Yes. []

SENATOR STUTHMAN: ...and as the senior member of the legislative body, the group that is here, I thought, my gosh, I didn't know that that had happened, but I've only been here six years. []

DAN MALONE: Well, yeah. []

SENATOR STUTHMAN: So...but I'm glad you cleared that up. I was... []

DAN MALONE: It was 20 years ago. []

SENATOR STUTHMAN: Yeah. So thank you very much for clearing that up. []

DAN MALONE: Yeah. Thank you. []

Transcript Prepared By the Clerk of the Legislature
Transcriber's Office
Rough Draft

Developmental Disabilities Special Investigative Committee
October 16, 2008

SENATOR LATHROP: Thanks, Dan. []

DAN MALONE: You bet. Thank you. []

SENATOR LATHROP: Is there anyone else interested in testifying today? Okay, that will conclude our hearing for today. We will reconvene tomorrow at 1:30 for additional hearing. Thank you. []